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# How-To Data Collection Series: The Evolution of the Focused Discussion Group: From Non-Participant to One of the Crew

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## How-To Data Collection Series: The Evolution of the Focused Discussion Group: From Non-Participant to One of the Crew

### Abstract

This article is part of The Weekly Qualitative Report's occasional series on "How-To Collect Qualitative Data." The qualitative data collection method described is that of focused discussion groups (FDG's). This method involves the moderator, or scripter as is the preferred term in focused discussion groups, to move beyond that of a non-participant data collector to that of an engaged participant-observer, observer-participant who is willing to get into the discussion with the participants and to provide accurate information to them while prodding them to discuss the topic in increasingly personally meaningful ways. Focused discussion groups are particularly helpful for working with marginalized, under-resourced populations around issues of health and poverty. Optimally, the scripter would share the sociocultural background of the participants.

### Keywords

Focused Discussion Groups, Focus Groups, Participant Observation, Health Information, and Marginalization

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## **How-To Data Collection Series: The Evolution of the Focused Discussion Group: From Non-Participant to One of the Crew**

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A growing number of participant observers are investigators who relate to and/or have lived the phenomenon under observation. Sheba Maraim George's *When Women Come First: Gender Roles in Transnational Migration* (2005) is a classic example. Searching for answers to questions that arose in her childhood and early adult life, she describes her journey from Kerala, India to California and back as a researcher who empathized with and lived the experience of gender resilience in the Keralite community in the US. It only occurred to me after reading Sheba's book for Dr. Chenail's qualitative research course that I realized just how much we had in common (she is a colleague and personal friend whose book I had finally read). Sheba is an accomplished and highly intelligent, deep thinker, qualitative researcher, and social scientist out of University of California, Berkeley. I'm a social scientist trapped in a medical doctor's body out of old school Harvard. So we got along smashingly from the start in 2003.

Before that in 1997, in true socio-medicalist form (some would say medical socialist for sharing my time without pay for years) I began to use what I then called "qualitative focus group research." We were at the edge of a new trend and wanted validation of our method in conducting focus group research about health related topics. So a cohort of faculty from Charles Drew University and UCLA were trained by Richard Kreuger on how to conduct focus group research in the vein of Madison Avenue marketing. We then applied lessons learned for health services research purposes. Dick Krueger was psyched about that and as often as possible probed for Madison Avenue application to Watts, Los Angeles type health issues. Seven years, two dozen projects and well over a hundred focus groups later, the lions share targeting inner city African

American and Latino health issues, two realizations hit home about the discussion groups I had moderated the past couple of years. First I had gotten involved. With a script in hand I asked questions, probed for answers, commented on them, answered questions asked of me by participants, and realized the discussions had digressed from the subjective, robotic role of focus group moderation about one specific topic and turned it into a debate of sorts. Men or women, Black or Latino, young or older, they were usually charged and energized conversations. I had taken and had given participants a 'poetic' phenomenological license. We laughed, we complained, we agreed and disagreed, we shared and cared, we met and made friendships but most importantly we learned. This brings me to the second realization.

A pattern was developing wherein participants were regularly making comments, English and Spanish speakers, that there was a need for more of these groups. The groups felt supportive. "We need more of these classes," was a comment that I heard often. What blew me away was that the focus groups were educational. Across gender and racial/ethnic make-up, participants labeled the discussion groups as a class and forum for expression of their own concerns. The made comments like: "We need to be able to say these things to the doctor." "They don't really understand what we go through." "Now that I've heard this I'm going to go for my mammogram." "I thought it was folks who ate a lot of sweets that got diabetes." "I didn't know I could get it because my father had it." Participants were learning building on what they heard from their maverick moderator and discussions with their peers. They were responding with new found understanding and were open about it.

These realizations made me see how unethical even ethical research can be. If I could collect the qualitative data I sought and beyond, why shouldn't we use these groups as a forum for learning as well? Many of the groups were held with marginalized populations who are difficult to recruit and who do not benefit from most of currently used written health information for reasons of limited educational attainment and limited literacy skills that come with poverty. When asked about written information about diabetes, a young man from a Watts housing project said, "You know what we do with that paper? This!" He then proceeded to roll-up an 8½ x 11 sheet of paper as if it were a joint and then took an imaginary drag. I could see the blue-white smoke back in college through my mind's eye as he exhaled to the group's roaring laughter. I was hysterical. We busted a gut that day.

Soon after I felt compelled to formalize the experience and christened the method Focused Discussion Groups (FDG) to differentiate them from traditional focus groups. In a "Centers for Medicare and Medicaid Services" funded study on breast cancer prevention among immigrant Latinas we tested the efficacy of two educational interventions at enhancing knowledge about breast cancer: FDG alone and FDG supplemented with an animated video on breast cancer and self breast exam training. Again, the ethics of "sound" research weighed upon me and so contrary to "good" science, I did not randomize the women into a control and intervention group in a randomized controlled trial. This would not have been fair to the control group who would have been surveyed and then given written information on where to get free exams. I was not as worried about them rolling up the written information as I was about not giving them information while I was on a roll.

I strongly feel that all participants in research should benefit and that all the women participating in the FDG should benefit while we were accruing robust qualitative data. Especially since we know immigrant Latinas in Los Angeles are a marginalized and vulnerable population. My mom was one. I'm not using and denying anyone's Mom for the sake of my ideas! Given its potential power to help a lot of people, I knew FDG worked but I still had to prove it. Educate and evaluate. To move things forward, two immigrant Latinas (a doctor from Belize and a Health Navigator from Mexico) were trained to conduct FDG with immigrant Latinas to ensure concordance with gender and political status. They were both empathetic women who were sharing knowledge about breast cancer and breast cancer prevention by correcting misunderstandings and by challenging cultural beliefs that were barriers to screening but always after querying those cultural beliefs first. They were trained to go with the flow. Where ever you go there you are! Then keep going.

I know now from having the benefit of formal qualitative research education that I went from non-participant to participant. From moderator with a script to reign in digression to an observer that hooked on to any point or counterpoint made and pulling it seamlessly into the same discussion in a different context. As if we were a bunch of people just chewing the fat--African Americans at barber shops, Latinos hanging out in front of the "bodega." Both consumers, in this case of information, as well as producers, of new thoughts, ideas, opinions, data! The FDG group members were learning as I prodded them on in various directions, that may have seemed counterintuitive to some, but always pulling the discussion back into the original theme in the finale.

FDG worked! For both groups knowledge about breast cancer increased significantly. At three months follow-up about 30% had been for mammography with no significant difference between groups. However, the group seeing the video and receiving breast cancer self breast exam training reported a significantly higher rate of self breast exams. The funders have their numbers and we have a new approach! Setting up a FDG is like setting up a focus group in nearly every detail. The difference lies in going from non-participant, beyond participant-observer to observer-participant educator. It's helpful to keep the following in mind:

1. FDG's give the moderator the poetic license to "get into it" with participants.
2. In FDG's, the moderator (scripter to differentiate from moderator) is made of the same or very similar social fabric to which key informants pertain.
3. This social fabric is the context in which the "learning group" discussions are framed and promulgated.
4. Scripters empathize with participants.
5. Scripters empathize with participating.
6. It's OK to be part of the fun. The data will be there when you stop enjoying yourself.

Focus Discussion Groups are a valuable participant-observer, observer-participant method for gaining robust qualitative data while imparting knowledge about health, particularly for vulnerable populations with limited education and limited literacy skills.

## References

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## Author Note

Dr. Calderón received a Bachelor of Science in Biology from the University at Albany, NY and an MD from Harvard Medical School. He trained in Family Medicine at the State University of New York's Brooklyn Health Sciences Center and practiced in underserved Latino and African-American communities in NYC until training in Neurology at New York University-Bellevue Hospital Medical Center. José completed a summer graduate fellowship in Epidemiology at the Bloomberg School of Public Health, Johns Hopkins University and a fellowship in Health Services Research with the Health Services Research Institute, AAMC, in Washington D.C. Currently, Dr. Calderón is Associate Professor, College of Pharmacy, Nova Southeastern University, and Associate Professor at the Charles Drew University of Medicine and Science, Los Angeles. He can be reached at College of Pharmacy, Nova Southeastern University, 3200 South University Drive, Fort Lauderdale, FL 33328-2018; Voice: 954-262-1296; Fax: 954-262-2278; Email: josecald@nova.edu.

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